An Orange Socks Story: Jessica and Johnny- Goldenhar Syndrome

Interview by: Gerald Nebeker, President of Orange Socks

Gerald: Welcome to the Orange Socks podcast, where we are inspiring life despite a diagnosis. I'm your host, Dr. Gerald Nebeker. In this episode, I speak with Jessica and Johnny by phone about their son, Griffin, who has Goldenhar syndrome. I thoroughly enjoyed learning about people with Goldenhar, and in particular, Griffin and learning about Jessica and Johnny's journey. Griffin is now eight years old, the second of three children. I know you're going to love hearing their story.

Gerald: Jessica and Johnny, thank you so much for taking the time to do an Orange Socks interview with me by phone about your son, Griffin, who has Goldenhar syndrome. Jessica, tell me a little bit about Goldenhar, I'm not familiar with it.

Jessica: Goldenhar syndrome is a congenital facial difference, and a lot of times, I like to explain Goldenhar like an umbrella, where Goldenhar is written across the umbrella, and under that are many things that your child could have with that syndrome. It usually involves incomplete development of the face as far as the ear, nose, soft palate, lips and the mandible things could be wrong. Along with sometimes internal problems with their organs like the heart, lungs, kidneys and spine and all of the things that can go along with that. Underneath Griffin's specific umbrella is that he is unilaterally affected on the left side. He has a small ear, and he is missing his cochlea inside of that ear and some other ear parts, which makes him 100 percent deaf on his left side. His jaw on his left side is underdeveloped, his face is asymmetrical. He has a heart issue called tetralogy of Fallot. He has spinal issues including scoliosis, and he also has a hypoplastic left thumb, which technically isn't usually under the Goldenhar syndrome umbrella, but as we've met with other families, we are actually finding out that a lot of children have some sort of a limb difference with their Goldenhar syndrome diagnosis. That's sort of a quick scenario of what Goldenhar syndrome can be.

Gerald: I appreciate that information. Johnny, what were your thoughts when you found out that Griffin had Goldenhar syndrome?

Johnny: It was interesting. We didn't find out until he was born, and even then we still weren't 100 percent sure what it was. It took the doctors a little bit to actually narrow it down. We knew in utero that he had tetralogy of Fallot, his heart condition that he had repaired four months after birth, but a couple of days after he was born, we realized that it's not just the heart, that there are other things going on. I think it was a little bit daunting to have other things added onto our plate or his plate right at birth. It was definitely a shock without that heads-up. We just kind of had to take it in stride, and we were at the mercy of the doctors at that point.

Gerald: Jessica, what have been some of the hard things that you, or Griffin, or your family has had to face with this diagnosis?

Jessica: The hardest things that we've had to face are probably navigating and juggling appointments, because with the list of things that he has to deal with comes a lot of clinics, a lot of specialists and a lot of surgeons, and so we are in a doctor's office a lot. I think that's maybe one of the challenges that we as a family have to face. For him, one of the challenges he faces right now at eight years old in the third grade is navigating the classroom. It has a lot to do with his hearing because he is deaf on his left side. We are trying to help him figure out some hearing aid options, and we've really been advocating for that. It has really been just funny because going back to when we found out Griffin's diagnosis, we had miscarried the year before with our second child, so when we had the diagnosis of the heart problem, we had an amniocentesis done so that we could know what to expect. He possibly could have had that open-heart surgery right after birth. Then that came back clear and everybody was relieved that it was just going to be the heart. Then when he was born and the room was quiet, a we knew there was something more. They finally diagnosed him with the Goldenhar, and all of these things came onto our plate, the scoliosis and the thumb and all of these things. We felt that because we had just suffered a loss with the miscarriage, he was here and he was alive, and he was relatively healthy even though he had all of these things on his plate. So, when Johnny and I talked about challenges, I had to really think, well, what is challenging? For us, it has just been what we do, it's just our life, and we're thankful for all of it because he's here and he's with us.

Gerald: That's great, so tell me about some of the joys that he's brought to your life.

Jessica: Griffin is an entity of his own. He is such an upbeat child and so positive. You would think that with all of the things that are on his plate that he would have a ho-hum attitude or really seem burdened, but this is just who he is and he absolutely loves it. A couple of months ago, we were talking about people, and my sister said that a lot of people feel bad for Griffin and take pity on him. We talked about what that was, and he just looked at me and said, "Why?" I said, "They feel bad that you have a facial difference, and they feel bad that you have all of these things that you have to do. You have to have surgeries and tests and procedures, and you go to all these appointments." He looked at me and said, "Well, that's just what I do," and he shrugged his shoulders. That's what brings the joy into our lives; he is the joy because his attitude is absolutely everything. He advocates for himself and is so comfortable in his skin, and he just owns who he is. That makes our entire life joyful. We do not see this diagnosis as a bad thing.

Gerald: That's super. Johnny, do you have anything that you want to add to the joys?

Johnny: The joys are that's all he is. I was trying to think of the times where we've had to really sit down with him and handle the negative issues that come along with this, and you can't count those on one hand. In the last eight years, I can't really

count the times that he's had a hard time mentally dealing with the stresses that come along with this. For his being eight-plus-years old, it's a great time with Griffin, really it is.

Jessica: I would definitely say another joy for us is sharing our story. Griffin is very proud of who he is, and he loves to tell people about himself. We love sharing our story with people, and that brings a lot of joy to our family, to be able to encourage others because of Griffin.

Gerald: He has an older sibling and a younger sibling, what impact has he had on his siblings as well as maybe some of your extended family?

Jessica: The way that Griffin's life has impacted Hunter, our oldest son, is that he has a lot of empathy. He has learned to advocate for not just his brother, but also himself. We have to advocate for Griffin and for our issues, so Hunter has learned to be a good advocate. Having Griffin in his life has helped him help others who have differences in a beautiful way. People have a lot of fear when they see people with differences because they don't understand what's going on, but when you're around somebody who has a diagnosis or a difference, it really helps you see them as a person. That has helped Hunter be overall a kinder person and a less fearful person. For three-year-old Hudson, I would say definitely he has more empathy and nurturing, he is such a nurturing boy. When Griffin had his hand reconstructed for his little thumb, it was fun to see Hudson step up in his own way and just be there and make sure Griffin was okay, that he had what he needed to drink or had a blanket.

Gerald: Johnny, do you have anything to add to that?

Johnny: I was just going to say that I think there is a fear that comes with being siblings of children with special needs, and I would imagine that that fear is always there. We don't want our lives to revolve around the medical issues of the one when we have other children. I'm proud of Hunter, our oldest. There are never any complaints or negativity whatsoever towards Griffin or animosity. It's always how can he help, what can he do to lighten the load. I really am proud of him and our extended family as well. We have a tremendous support group on both sides of our family. There's never a situation where we couldn't ask for help, we've been very blessed in that department.

Gerald: That's awesome. Jessica, I'm curious, if I came to you, new to this diagnosis with a child with Goldenhar syndrome newly diagnosed, what advice would you give me?

Jessica: The first thing I would say is to take a deep breath and to lean on a couple of things. Lean on any support you have and lean on your faith. Many people say to us, "I don't know how you're doing things." We are always busy, there is always something with Griffin. Johnny and I say all of the time that it's like the Lord has

given us so much peace and so much guidance that it's a super natural miracle that we have been able to handle the things that we've handled with such grace. Definitely lean on your faith and your support. There are other things that I've learned and that have been so good for us. The first thing I learned is early intervention with Griffin. There are many pieces to him. He has the hearing deficit, and there is the facial stuff, and there's the scoliosis, and there's the thumb which is orthopedic. The best thing that happened to us is that we were plugged into early intervention through our school system and through our state. Within the second year of Griffin's life, I had therapists in my home helping with him, speech therapists and orthopedic therapists, all for free. I had no idea things like that existed. He immediately had his IEP created, his Individualized Education Program, within just a couple of weeks of life, and that's followed him until now. That same IEP is still with him. Plug into the resources that are available to you and do not be ashamed of that and don't shy away from that. With his hearing difficulty and his speech and everything else, that really helped him keep up with all of the things. He does miss a lot of school. With the support thing, make sure that you are leaning on your family and your friends. Something we didn't do from the beginning was to connect with other families that had similar diagnoses. I had been following the CCA, the Children's Cranial Association, for years, but since we had a great support system, I didn't feel that we needed that when he was little. I didn't feel any need to connect with other families, and this past summer, we were able to go on a retreat where he was able to meet other kids which was fantastic for him at his age. Johnny and I were overwhelmed meeting these families and these parents who spoke our language. We didn't even know we needed this because we have great support system, but it was like we had something in common. Making the connection was huge. The last thing I think I would tell you if this was a new diagnosis to your child is to not be fearful of advocating for your child, whether that be educationally or medically. I'm a very passive person, but I have had to learn to really stand up for him and our family with doctors and nurses. 95 percent of our experience has been fantastic, but every so often, you're just not being heard and not being seen, and we've had to say something. I've had to push my feelings aside, and I've had to say what I've needed to do. We've actually switched care systems completely and doctors and departments completely because we didn't feel heard. I want to empower parents to advocate for their child and to trust your heart and your gut.

Gerald: That's awesome. Johnny, do you have anything to add?

Johnny: I would say to take advantage of technology. Nowadays, we have so much knowledge at our fingertips. Like Jessica said, we knew that organizations like CCA existed because we would run across their newsletters, so don't be afraid to reach out and to ask people questions. You would research anything else in your life, so don't be afraid to research and to ask other parents who have gone down these roads before you if they could save you from trial and headache. I know we are more than willing, we love being able to talk to people about the situations that we've encountered and what we've done right. I get excited that as technology advances, we can connect with these people on the other side of the planet. Just the other day,

someone messaged Jessica from UAE, United Air Emirates, almost in a panic asking, “My child has Goldenhar syndrome, what do I do?” He had question after question. It’s amazing being able to help someone on the other side of the planet just at our fingertips, and it doesn’t cost anything.

Gerald: Jessica, do you want to have the last say?

Jessica: I think our hearts ache for parents who maybe are facing a diagnosis with a child with a facial difference or any diagnosis, knowing how much joy there is in it. I pray for you, and I want to encourage you and those of us that have walked through it. Through Orange Socks and other organizations, you’ll discover how much joy these children bring into our lives, and know there’s hope and that your lives will be so much richer because of these children. All of the medical problems, and all of the hardships, and all of the challenges will dissipate into your story, because the hope and the joy will rise to the top. That is the truth. We are thankful that we can tell our story and that Griffin’s life will have a purpose in that way. Thank you so much for letting us tell that story.

Gerald: I was very interested to learn more about Goldenhar syndrome. I hadn’t heard about it before, although I am certain I have seen people with it over the years. Jessica mentioned that she had met a pastor with Goldenhar and his wife at a meeting with people with craniofacial issues. She also said that many people with Goldenhar syndrome get married, go to college and have successful careers. With the attitude that Griffin has already displayed, I’m sure he will be one of them. Thanks for listening to his episode. Orange Socks is an initiative of Rise Incorporated, a non-profit organization dedicated to supporting and advocating for people with disabilities. Follow Orange Socks on Facebook and Instagram, and visit our website orangesocks.org for more stories and to find national and local resources to help parents of children with disabilities.